



VWD CONNECT FOUNDATION

NEWSLETTER

DECEMBER 2024



Inaugural Provider Education Workshop a Huge Success

The VWD Connect Foundation hosted its inaugural Provider Education Workshop on Severe Von Willebrand Disease (sVWD) *November 8-10, 2024,*

in West Palm Beach, Florida. This groundbreaking event brought together a multidisciplinary group of healthcare professionals, including hematologists, genetic counselors, nurse practitioners, RNs, and social workers, fostering collaboration and knowledge sharing.



For attendee Lucas Lopez, a genetic counselor from Atlanta, GA, the Workshop was his first introduction to the Foundation. "The weekend was a fantastic opportunity to learn from experts and those affected

with severe VWD," he said.

"I'm looking forward to taking what I learned and positively impacting the patients I care for." He's not alone in that sentiment – in a post-event survey, 100% of respondents agreed that they now have new resources to share with their sVWD patients. He added, *"I have already*

recommended the July conference to one of my patients!"



Lucas Lopez (right), workshop attendee and winner of the Foundation's officially unofficial Halloween costume contest, and his Halloween inspiration: Faculty member Dr. Robert Sidonio!

Sessions covered diagnosing and managing sVWD, addressed challenges like prophylaxis, GI bleeding, and reproductive health, and featured case studies from experienced providers. Curriculum also included updates from industry professionals and Foundation research committee members. Similar to the annual patient conferences, these topics were addressed in large group sessions and further explored in smaller break-out groups.

However, these attendees weren't quite as well-behaved as their summer conference counterparts. The providers brought their own flair, holding their breakout discussions by the pool!



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*Provider Education Workshop
continued from page 1*

One standout session was the Patient Panel, where six Foundation members shared personal experiences to promote patient-centered care. This unique opportunity allowed providers to hear directly from patients about their challenges, fears, and hopes for sVWD healthcare. Attendees also enjoyed engaging activities, including a game night, wellness sessions, and live music, blending education with community-building.

This event expanded upon the Foundation's mission and generated a new momentum within the provider sphere. In the post-event survey, 100% of respondents expressed interest in attending another Provider Education Workshop. The Foundation has already announced dates for next year's event: **November 14-16, 2025!** •



**VIRTUAL EVENT
BOOK CLUB:
MOVIE EDITION**

**WEDNESDAY, JANUARY 8
8:00PM EST**

Help us choose a movie to discuss for our January Movie Edition of Book Club! **EMAIL** or **MESSAGE** your pick and the movie chosen will be announced at our Holiday Party (and of course in an email).

**VIRTUAL EVENT
MONTHLY MEMBER MEETUP**
THURSDAY, JANUARY 23 • 8:00PM ET

SPECIAL EDITION: THE STATE OF THE FOUNDATION
Our January Monthly Member Meetup will be taken over by the State of the Foundation 2025. This annual meeting is a time for our community to regroup, reflect on last year, and learn about Foundation news, research, and events for 2025. There will be time to share questions or suggestions as well!

[PRE-REGISTER HERE](#)



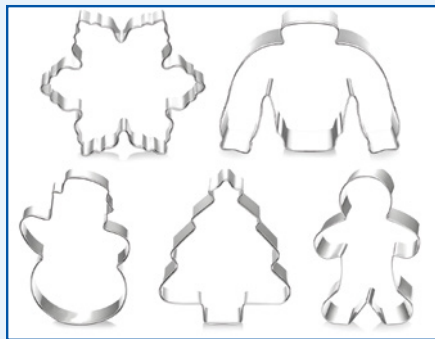
VIRTUAL EVENT

VCF Holiday Party

MONDAY, DECEMBER 16 • 8:00PM ET

Join us for a festive VWD Connect tradition: our annual Holiday Party! Back by popular demand, we will be holding a cookie-decorating session with our very own Heather Hoiseth.

Make sure to check out the recipe below first to pre-bake your cookies, make your icing, and come ready to decorate! We'll even help with the supply list! Pre-register by **December 10** to receive these adorable cookie cutters, powder and a frosting/piping kit!



[PRE-REGISTER HERE](#)



CUT OUT SUGAR COOKIES

- 2 cups butter (4 sticks)
- 2 cups sugar
- 2 teaspoons vanilla extract
- 1 teaspoon salt
- 2 teaspoons baking powder
- 2 eggs
- 6 cups all purpose flour, sifted

Cream together butter and sugar until pale and fluffy at medium speed, scraping bowl with spatula as needed. Beat in eggs and vanilla at slow speed until equally mixed.

Combine dry ingredients in a separate bowl, then gradually add to butter mixture at slow speed, occasionally scraping bowl. After all dry ingredients are added, turn mixer on high speed for a few seconds to really combine the ingredients well.

Roll out dough in batches of equal thickness between two pieces of parchment paper, then carefully cut with **COOKIE CUTTERS**. Bake at 350° F on a cookie sheet with parchment paper for 10-12 minutes, until edges are slightly brown. Cool before frosting.

ROYAL ICING

Mix together until frothy

- 1/3 cup **MERINGUE POWDER**
- 1/2 cup warm water
- 2 teaspoons vanilla

Slowly add:

- 2 pounds powdered sugar
- 1 tablespoon corn syrup

Continue to mix for 3 minutes on medium/ medium high. Icing will start to turn white and look fluffy. Do not overmix.

Add water in small amounts to control consistency. You will need thicker icing for detailing, and thinner icing for the base layer. Add food coloring of your choice.

Use the **PIPING BAGS AND TIPS** to decorate the cookies.

DECEMBER RESOURCES

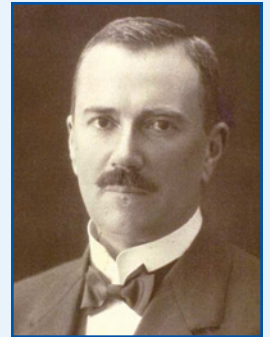
DECEMBER 1 NATIONAL COOKIE CUTTER DAY

Take this as a sign to pre-register by December 10 for our cookie-decorating Holiday Party and receive some festive supplies!

DECEMBER 8 PRETEND TO BE A TIME TRAVELER DAY

See if you can match the year to the VWD-related historical event! The first five people to [EMAIL](#) or [MESSAGE](#) a screenshot of the correct answers will win a prize! Please no outside sources.

- 1926 _____ A. Four-year-old Ashanthi de Silva becomes the first gene therapy success story
- 1948 _____ B. First successful cloning of the Factor VIII gene
- 1971 _____ C. ISTH BAT (Int'l Society on Thrombosis and Hemostasis - Bleeding Assessment Tool) is published
- 1984 _____ D. National Bleeding Disorders Foundation (formerly NHF) opens as The Hemophilia Foundation, Inc.
- 1986 _____ E. First effectively virus-inactivated factor VIII plasma product is approved in the U.S. for hemophilia A
- 1990 _____ F. First recombinant von Willebrand factor treatment approved in U.S. for VWD
- 1992 _____ G. First issue of VWD Connect Foundation's monthly newsletter
- 1999 _____ H. Zimmerman *et al.* identify the protein now known as von Willebrand factor (vWF)
- 2010 _____ I. First recombinant FVIII product is approved in U.S. for hemophilia
- 2011 _____ J. [ERIK VON WILLEBRAND PUBLISHES DISCOVERY OF VWD](#) ([click pic for more](#))
- 2015 _____ K. First successful AAV8 gene therapy performed for hemophilia
- 2017 _____ L. First virus-inactivated factor VIII plasma product approved in the U.S. for VWD
- 2023 _____ M. VWD Connect is founded/[FIRST NATIONAL CONFERENCE FOR TYPE 3 PATIENTS](#) ([click pic for more](#))



DECEMBER 17 SATURNALIA

Read this [ARTICLE](#) from the Getty Museum about "The Wild Holiday that Turned Ancient Rome Upside Down!" Along with a short history lesson, you might find some traditions that pique your interest.



DECEMBER 14 BIRD COUNT DAY

In 1900, ornithologist Frank Chapman suggested dedicating a day to bird *counting* rather than bird *hunting*. Click the cardinal to join in on the fun with thousands of other birdwatchers!

Jessica Wolfe

How did you connect with the Foundation?

I've been a Foundation Member since the beginning. I'm so proud to be a part of this community and this work!

Where do you live? What would you recommend a first-time visitor explore?

We live in Michigan with our sons Kadin and Reese, and two dogs. Any first-time visitor should definitely check out the Great Lakes... Lake Michigan is the best!



KADIN, JESSICA, ERIC AND REESE

How many conferences have you attended, and what has your experience been like?

I've attended five conferences, including the first one, and have loved all of them. Meeting other Type 3s has been invaluable and this community is so encouraging and supportive.

How was your experience on the Patient Panel at our Provider Education Workshop?

I was thrilled to be part of the Provider Workshop. It was really encouraging to see so many providers come together to learn more and share best practices about severe VWD. Being on the panel was a little scary, but I'm such an advocate at heart, I really wanted to speak up. I want doctors and providers to understand that we are experts in our VWD as well, and have our own lived experience that should be valued as much as their medical knowledge. We need to be a team and tackle this thing together.



ON THE PATIENT PANEL

Did you learn anything new?

From conversations with some providers who were there, I learned that there are sometimes

things behind the scenes that may prevent them from giving the kind of care we are seeking. That kind of shared understanding builds empathy and bridges to collaborate moving forward. We can solve these problems together.

Your husband Eric also attended the Workshop, as both a companion and the official event photographer. Eric, what has been your experience accompanying Jessica to Foundation events and being her support?

I've grown in understanding of severe VWD from a science standpoint and from a far greater understanding of the hope of richness of life that can be lived with thoughtful treatment plans and encouragement from others in the community.

What was it like being behind-the-scenes as a photographer?

It was a privilege to watch the community of patients, caretakers and providers all come together in collaboration and desire to help grow forward in health.

Thanks, Eric and Jessica!



TAKEDA is sponsoring a study that will begin enrolling for a Phase 3, Prospective, Open-label, Uncontrolled, Multicenter Study on Efficacy and Safety of Prophylaxis With rVWF in Children Diagnosed with Severe Von Willebrand Disease. For more information click [HERE](#)

NEW YORK BLOOD CENTER ENTERPRISES is involved in a research study actively recruiting individuals with bleeding disorders. Eligible participants will be asked to donate samples of their blood. The purpose of this study is to better understand antibody therapy that can address blood clot formation through the examination of source plasma collected from donor blood. Eligible participants for

the study would be individuals with a reported bleeding disorder willing to donate blood for research purposes. For more info, click [HERE](#) to email Stephanie Dormesy.

THE AMERICAN THROMBOSIS AND HEMOSTASIS NETWORK (ATHN) sponsors the ATHN-dataset, a large set of de-identified data contributed by persons with blood disorders in the United States. The health information that makes up the ATHNdataset is helping us gain a better understanding of blood disorders so that together, we can transform care and improve lives. Ask your provider to include your data in the ATHNdataset! To learn more, click [HERE](#) to see the ATHNdataset Brochure.

VWD CONNECT FOUNDATION is recruiting severe Von Willebrand Disease patients to enroll in the Severe Von Willebrand Disease (sVWD) Patient Registry. This is your opportunity to have your voice heard! For more information, click [HERE](#)

VEGA THERAPEUTICS, INC. is sponsoring a VWD Clinical Trial that is now enrolling for the VIVID 2 Study (NCT# 05776069) of a new drug called VGA039 as a single subcutaneous administration for Von Willebrand patients who are symptomatic, ages 18-60 years old. Interested in learning more? Click [HERE](#) or contact your provider. •

COMMUNITY CORNER

Behind everything the Foundation does is our community of supporters that make our connections possible. Click on the logos below to learn more about our wonderful sponsors!

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